Ethical issues in diagnosis and management of patients in the permanent vegetative state

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Gastrostomy feeding has been withdrawn from around 20 people diagnosed as being in the permanent vegetative state in the United Kingdom, inevitably resulting in their death from dehydration. The clinical diagnosis is confirmed by healthcare professionals and legality is conferred by the courts, but the ethical position is not formally considered. This article outlines some specific ethical issues.

Summary points

- The diagnosis of the permanent vegetative state cannot be absolutely certain
- There is no standard test of awareness and data on prognosis are limited
- Patients in the permanent vegetative state raise ethical issues concerning the nature of consciousness, quality of life, the value society attributes to life, and handling of uncertainty
- In an era of increasing demands on healthcare resources decisions have to be made about allocation of limited resources and how quality of life is to be judged

Permanent vegetative state

The permanent vegetative state is diagnosed when a patient is unaware of himself or herself and his or her environment and there is no prospect of any change in this state by any means. The clinical characteristics and diagnosis of the condition have been established (box).[1–6] Nevertheless, the clinical diagnosis is not always easy because there is a spectrum from the vegetative state to full awareness. The border between these two states is referred to as the low awareness state.[1] No absolute definition exists for low awareness state. Generally, however, the patient behaves in a way that implies that at times he or she may be able to extract meaning from a stimulus and may be able to respond in a goal directed way. Usually the state is intermittent, with only vegetative responses being present at other times. Rarely, it may be possible to establish some form of rudimentary communication. We do not know if patients have any day-to-day memory or appreciation of their situation or whether they can experience somatic or emotional pain or pleasure.

Legal position

The legal argument is straightforward. Patients must consent to any treatment they receive; otherwise the doctor is liable to a charge of battery. Patients in the vegetative state are unable to give consent, both literally and legally (in terms of their mental capacity). Therefore they can be treated only if it is in their best interests. That question can be referred to the High Court. "The question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."[7] In every case the High Court has decided that a patient in the permanent vegetative state does not benefit from continued treatment and has given permission to stop treatment. It does not decree that treatment must stop.

There may be a logical inconsistency in the legal position.[8–10] The law states that the patient in a permanent vegetative state has no interest but also concludes that treatment is not in the patient's best interests. If someone has no interest, how can they also have a best interest? Counter arguments have been put forward.[11]

Diagnosis of permanent vegetative state

The patient shows no behavioural evidence of awareness of self or environment
There is brain damage, usually of known cause, consistent with the diagnosis
There are no reversible causes present **and**
At least six (and usually 12) months have passed since onset

Ethical issues

This article focuses on the specific ethical aspects of managing patients who are (or may be) in the permanent vegetative state. It does not consider the ethical questions that may arise before the eventual diagnosis of permanent vegetative state. The box lists the stages involved in a decision to stop treatment in the order they are likely to arise. Each has its own ethical issues.

Stages of decision making

Recognising that the permanent vegetative state may exist and that treatment might be stopped
Diagnosing the vegetative state
Deciding on its permanence
Deciding to withdraw treatment
Process of withdrawing treatment

Considering that treatment might be stopped

Two factors may prevent the option of stopping treatment being considered. Firstly, the responsible health staff may not accept that it is ethically allowable and may therefore not raise the issue. In other words, personal beliefs about a moral issue may preclude others from making their own choice. Secondly, the organisation may not allow the process to start, perhaps believing it will be too expensive or will reflect badly on it. Again choice is being curtailed without discussion or consideration. It may, however, be illegal (and possibly unethical) to continue feeding once the patient is known or suspected to be in the permanent vegetative state.[12]

Therefore the first ethical question is: if someone is in the permanent vegetative state is it ethical to continue feeding them (which constitutes continuing assault because they have not given permission) without a full consideration of the matter by all interested parties, probably including the High Court in the United Kingdom?

Diagnosis of vegetative state

Diagnosing the vegetative state is difficult as there is no definitive test for awareness. The neuroanatomical substrate and neurophysiological mechanisms underlying consciousness are still not understood. Indeed the nature of consciousness itself is the subject of much philosophical and neuropsychological debate.[13] Consequently there is scope for uncertainty and error.

This contrasts with the case for "brain death," where the neuroanatomy and neurophysiology are both well established.[14] The vegetative state is simply one end of a spectrum of awareness, and there is no obvious cut-off between the vegetative state and the low awareness state.[1] Three ethical questions arise: in the absence of any test, can we accept that any human being is unaware? if so, can we equate the vegetative state (or some other set of specified clinical observations) with unawareness? and what level of uncertainty about the diagnosis of vegetative state is acceptable?

Establishing permanence

Similar uncertainties arise concerning the prognosis of patients diagnosed as being in the vegetative state. Interest in the vegetative state has risen because of its legal importance, and this has increased the amount of study. But we do not know whether the vegetative state as it is diagnosed now is comparable with the diagnoses made five, 15, or 50 years ago. Consequently it is difficult to evaluate much of the evidence, which is anyway weak. The anecdotes of late recovery are difficult to substantiate, and we do not know how certain the original diagnosis was or how good the recovery was. We therefore need to consider what level of certainty about the prognosis for any recovery is acceptable and whether the level of potential recovery (for example, to a low awareness state) should alter the considerations.

Decision to withdraw feeding

The decision to withdraw feeding, which is made by the High Court, needs to be set in a consistent and comprehensive ethical framework such as respect for autonomy, non-maleficence, beneficence, and justice.[15]

The patient's autonomy is completely compromised by being in the permanent vegetative state as she or he apparently cannot comprehend any information and certainly cannot communicate any wishes. The High Court acts on the patient's behalf and decides whether it is in the patient's interests to continue treatment.

Nevertheless, some aspects of the patient's autonomy could be considered. The patient may have had pre-existing wishes, such as a wish to donate organs. We also have to consider the patient's perspective of being treated as a non-sentient person with loss of privacy and dignity. Although care staff generally are extremely thoughtful and, in my experience, do respect the patient as a person, undoubtedly this will not be true at all times or in all places. Rape has been reported.[16] The ethical question is: should the decision process consider other aspects of a patient's autonomy such as their pre-existing wishes and the inevitable, if rare, slip in the standard of humanitarian care?

Non-maleficence refers to the avoidance of doing harm, and beneficence refers to doing good. If the patient is truly unaware then it is presumably difficult to do either harm or good. The patient truly has "no interest," and the High Court has decided that such patients gain no benefit from continued treatment given without consent.

This judgment will become more difficult once the low awareness state starts to be considered. There could, for example, be extensive arguments about whether continued existence in a low awareness state is worse than being dead. Ongoing treatment could then be argued to be harmful. This might apply both to patients in the permanent vegetative state in whom prognosis was uncertain and to patients in a persistent low awareness state. In future we are therefore going to have to consider whether the possibility of recovery into a lifelong state of low awareness and severe disability should be considered beneficent or maleficent.

Justice, which includes equity (the fairness of the decision for other people), has not so far been considered explicitly in the context of treating patients in the permanent vegetative state. Continuing to support such a patient denies many other patients access to scarce health resources. However, the decision not to support the patient may alter the general perception of the value of life—for example, leading to changes in attitude towards severely disabled people not in a permanent vegetative state. Therefore the questions to be asked are: is it equitable to allocate substantial scarce resources to someone who is unaware of their situation and who will not recover awareness? and is it worth taking the risk that deciding to withdraw treatment from one group of disabled people (those in permanent vegetative state) may cause secondary

harm to other disabled members of society? The third, provocative, question not yet faced is whether it is equitable to devote substantial resources to someone who is unaware or scarcely aware of the intervention and their situation and who will not recover any substantial autonomy—that is, independence.

Mode of death

The last ethical question relates to the mode of death. Stopping food and water inevitably leads to death within 14 days from dehydration. Conscious people suffer greatly if they die from dehydration. Moreover, this mode of death precludes the use of any organs for transplantation, which may run counter to the patient's known wishes. It would be possible to kill the patient more directly. This might reduce the stress on and distress of relatives and health staff and allow the organs to be used, which could satisfy at least some of the patient's previous autonomy. The situation is similar to treating terminal distress in a conscious patient. We need to decide therefore whether a more direct, quicker mode of death should be allowed that would enable some organs to be used for transplantation.

The future—broaden the interests considered

Society has responded to the problem of patients in the permanent vegetative state by concentrating solely on patients who are undoubtedly unaware and on the specific interests of the patient, finding a legal way to allow the generally acceptable decision to be reached. As discussed above, many ethical questions remain unresolved and problems will soon arise. People who are on the margins of permanent vegetative state will increasingly come before the court. Someone may challenge the medical and legal logic of the present process, perhaps by taking a doctor to court for failing to withdraw treatment.

One solution is to broaden the consideration to include other parties and to use a full ethical accounting procedure. Thus for each question raised above (and for others I have not considered) we could first agree whose interests are legitimate and then consider each party's interests from the point of view of autonomy, beneficence, non-maleficence, and justice. The box gives some of the potential interested parties. The main bone of contention is likely to centre on justice—is it equitable to allocate so much scarce resource to one person who is unaware for most of the time? This will not be an easy question to answer. Although healthy people may rate the quality of life of someone in the low awareness state as very low, the quality of life of people who have a specific chronic illness is determined by social factors and not the disease or impairment, and they usually rate their quality of life as reasonable.[17] Patients in the low awareness state seem to want to go on living.[18 19] Consequently, we cannot appeal to externally imposed judgments on quality of life. We may simply have to face either rationing that culminates in the premature and avoidable death of a few people or allocating increasing resources to people who are gaining minimal benefit as judged by most other people.

Interested parties and their interests

Patient
- May have pre-existing statement of wishes in this situation (an anticipatory decision)
- May have wished to donate organs
- May have had strong beliefs (religious or otherwise)
- May or may not be experiencing emotions

Relatives (and friends)
- May have financial interests (for example, will or settlement)
- May have other legal interests
- May have emotional or other stressful experiences
- May be ignoring children or others
- May have strong beliefs

Ward staff
- May have emotional interests in patient or family
- May have strong beliefs

Organisation giving care
- May have financial interests (positive or negative)
- May have political or public relationship interests

Organisation funding care
- May wish to allocate resources differently

Society
- May wish to preserve sanctity of life
- May wish to avoid "slippery slope"
- May support different allocation of resources

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1 *International working party report on the vegetative state*. London: Royal Hospital for Neurodisability, 1996.
2 Quality Standards Subcommittee of the American Academy of Neurology. Practice parameters: assessment and management of patients in the persistent vegetative state. *Neurology* 1995;45:1015-8.
3 Working Group of the Royal College of Physicians. The permanent vegetative state. [Addendum 1997;31:260.] *J R Coll Phys* 1996;30:119-21.
4 MultiSociety Task Force on PVS. Medical aspects of the persistent vegetative state. Part 1. *N Engl J Med* 1994;330:1499-507.
5 MultiSociety Task Force on PVS. Medical aspects of the persistent vegetative state. Part 2. *N Engl J Med* 1994;330:1572-9.
6 Wade DT, Johnston C. The permanent vegetative state: practical guidance on diagnosis and management. *BMJ* 1999;319:841-4.
7 Airedale NHS Trust *v* Bland. AC 1993:789, 868.
8 Fenwick AJ. Applying best interests to persistent vegetative state—a principled distortion? *J Med Ethics* 1998;24:86-92.
9 Fenwick AJ. Best interests in the persistent vegetative state? *J Med Ethics* 1999;25:59-60.
10 McClean SAM. Legal and ethical aspects of vegetative state. *J Clin Pathol* 1999;52:490-3.
11 Gillon R. Persistent vegetative state, withdrawal of artificial nutrition and hydration, and the patient's "best interests." *J Med Ethics* 1998;24:75-6.
12 Andrews K. Vegetative state—background and ethics. *J R Soc Med* 1997;90:593-6.
13 Cotterill R. *Enchanted looms. Conscious networks in brains and computers*. Cambridge: Cambridge University Press, 1998.
14 Quality Standards Subcommittee of the American Academy of Neurology. Practice parameters for determining brain death in adults. *Neurology* 1995;45:1012-4.
15 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 4th ed. New York: Oxford University Press, 1994.
16 Roberts J. US rape case leaves ethical uproar. *BMJ* 1996;312:329.
17 Dijkers M. Quality of life after spinal cord injury: a meta-analysis of the effects of disablement components. *Spinal Cord* 1997;35:829-40.
18 Homer-Ward MD, Bell G, Dodd S, Wood S. The use of structured questionnaires in facilitating ethical decision-making in a patient with low communicative ability. *Clin Rehabil* 2000;14:220.
19 Shiel A, Wilson BA. Assessment after extremely severe head injury in a case of life or death: further support for McMillan. *Brain Injury* 1998;12:809-16.

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